

**Voluntary Assisted Dying**  
**National Press Club 12<sup>th</sup> October 2017**  
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I acknowledge the traditional owners of the land on which we meet and give respect to Elders past and present.

The desire to live is the strongest of human instincts. We fight for our own lives. We fight for others to live.

Most people want to extend their life for as long as they can, and many will endure pain and suffering when there is hope of recovery or improvement.

We see our patients with terminal illnesses fighting to hold on, looking to a new treatment or investing in the hope of a new trial.

As families and friends, we stand with them. As doctors we fight for them.

Despite this instinct there is also an acute awareness of our own mortality.

People with incurable diseases make decisions about accepting and refusing treatment in our health services every day - weighing up their hopes against their suffering.

To seek death in the form of voluntary assisted dying, to go against the instinct to live, speaks to something stronger.

It speaks to how a person chooses to prioritise the quality of their life over its quantity.

Voluntary assisted dying is not about giving up the fight to live. It is about the relief of suffering of people who are dying. It is about compassion, choice and control.

It recognises that some people at the end of life may choose to have control and not endure further suffering when their only prospect is decline and imminent death.

Voluntary assisted dying is not about a choice between life and death. No. Rather, it is about respect for a dying person's choice, about the timing and manner of their death.

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For the first time in Australia, a Bill sponsored by a state Government, to legislate Voluntary Assisted Dying is before the Victorian Parliament for debate.

More than 30 attempts to legislate a form of voluntary assisted dying in the various states have failed. In some cases, deservedly so.

The one exception was of course the Rights of the Terminally Ill (ROTI) Act 1995 of the Northern Territory which was subsequently overturned by the Federal Parliament.

What sets apart this Victorian Bill is the process.

After considering 1074 submissions and hearing from 154 witnesses, as well as travelling to a number of jurisdictions where forms of voluntary assisted dying exist, the cross party Committee recommended that the Victorian Parliament legislate voluntary assisted dying for people who are suffering from a terminal illness.

In response the Victorian Government established a Ministerial Advisory Panel and asked me to chair it. I want to acknowledge Premier Andrews and Minister Hennessey for their leadership in following this process.

My fellow panellists consisted of six distinguished individuals with backgrounds in palliative care, the law, consumers and the disability sector. I want to take this opportunity to thank them and the staff from the Department for their dedication and hard work.

It was a particular honour for me to work alongside Professor Ian Maddocks, Australia's first palliative care physician, the father of palliative care in Australia. A mentor of many physicians and a compassionate advocate for his many many patients.

Our role as a group of experts was to make recommendations about how voluntary assisted dying could be legislated and implemented in Victoria. It has been a careful, considered and thoughtful process.

While the Parliamentary Committee offered a framework, we had much to do. We consulted. There were 14 stakeholder forums with 300 attendees, well over 100 submissions and targeted consultations as well.

We considered the feedback, research and available evidence. We extensively debated each point to reach a consensus. There are aspects of the Committee's suggested framework that we changed and we added additional detail and safeguards.

Our report, with its framework for voluntary assisted dying in Victoria, with its 66 recommendations, including the 68 safeguards were accepted in its entirety and are mirrored in the Bill that will be debated by the Victorian Parliament next week.

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To summarise, the legislation will provide access to voluntary assisted dying for those people who are dying and who are suffering.

The eligibility criteria to access voluntary assisted dying are the following. The person must be an adult, who is ordinarily resident of Victoria; who has decision making capacity in relation to voluntary assisted dying; who has an advanced, progressive, incurable illness, disease or medical condition; that will cause death; that is expected in weeks to months but no longer than 12 months and is causing suffering that cannot be relieved in a manner that is tolerable to the person.

As a Panel, we spent considerable time on the 12-month outer limit. It is there for two main reasons, first it provides clarity and certainty for those individuals who want to access voluntary assisted dying and their assessing doctors.

Second, it provides allowance for diseases with longer time courses such as motor neuron disease who may otherwise find it difficult to access voluntary assisted dying. We felt that it was very important that this group not be excluded.

What the Panel has done is to learn from other jurisdictions but not just copy them. What we have done is to make the legislation the right legislation for Victoria. It is unique.

The person must make three requests to access voluntary assisted dying. One of these requests must be in writing and signed by the person and two independent witnesses in the presence of their medical practitioner; this document is a very important.

Two senior medical practitioners must be satisfied that the person not only meets all of the eligibility criteria but also be satisfied that the person's request is voluntary and free of coercion; that the person is informed not just about voluntary assisted dying but also their other treatment options and palliative care. They must assess the request as being enduring.

The person will need to make their final request at least 10 days after the first request, and the person may withdraw from the process at any time.

When the request and assessment process has been satisfactorily completed, the co-ordinating doctor may prescribe the lethal dose of medication to the person who will then self-administer the medication at a time of their choosing.

There is an exception for a person who cannot digest or physically administer the medication themselves. This can happen, for example, with gastro-oesophageal cancer where a person can end up unable to swallow. In these circumstance the co-ordinating medical practitioner will be able to apply for a separate permit to administer a medication to the person at the time of the person's choosing.

This is an important safeguard. A person should never feel the need to either access voluntary assisted dying or consume their medication because they are concerned that they might lose the capacity to swallow or consume a medication themselves.

There are of course many other details and safeguards. There are specifications surrounding the qualifications, expertise, seniority and required extra training for medical practitioners.

The prescription, dispensing, storage, usage and return or disposal of the medication are subject to monitoring.

There is strong oversight, including the review of each assessment, through a Voluntary Assisted Dying Review Board.

There are also strong deterrents through the creation of new offences.

The Panel is confident that the legislation balances respect for personal autonomy with strong safeguards that protects the community.

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While the details of the Bill are important, what I want to address is why? Why should we have Voluntary Assisted Dying?

What makes a former President of the Australian Medical Association, a neurosurgeon who spends their professional life working to save and preserve life, including through public health advocacy, support voluntary assisted dying?

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Like many people, my opinions have been shaped by my experience both professional and personal. I have seen the great palliative care that my grandmother received when she died of breast cancer. She died in a hospice, with loving care from her family and from the staff.

I have seen the bad as well, including my father who starved to death, unable to eat, unable to drink, literally rotting in his bed as the ulcer on his sacrum grew. He couldn't communicate but he was suffering and in pain.

I watched, President of AMA NSW and a consultant neurosurgeon, hopelessly unable to help him. Resources and access were not an issue. I remember my despair as I politely asked one of his doctors for help to ease his suffering. He died a terrible death.

My father did not have decision-making capacity as he approached death, and he would not have had access to voluntary assisted dying under the proposed legislation.

However, there are too many people who suffer, and suffer needlessly, when they are dying that do have the capacity to make a decision about the manner and timing of their death.

For the majority of people, their symptoms can be well managed by good medicine and palliative care. But the issue is that for some, even the best of palliative care is not enough.

We have heard these accounts again and again as we talked to people during the consultation process and since.

It is those people, who do have the capacity make decisions about their own death that we can, and should help through this legislation.

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One of the guiding principles for the Panel in making our recommendations was that personal autonomy should be respected.

So many of the arguments against the proposed legislation disrespect that notion of personal autonomy.

A central tenet of the proposed legislation is that it is an informed and voluntary decision of the person.

Opponents take a paternalistic view about people who seek assistance to end their suffering when they are dying.

When a person becomes ill, there is a tendency to lose perspective of that person's autonomy and intelligence. In many cases these people have held positions of responsibility, running companies or businesses, raising children, making important life decisions for them and their families.

Most people who are dying of an incurable disease, illness or medical condition still retain all of those same cognitive skills and abilities.

The arguments that suggest that because a person is suffering and dying, a decision to ask for voluntary assisted dying means that they are not of sound mind are not only paternalistic, they are offensive.

What people want at the end of life is control, autonomy and independence. These qualities, amongst others, are consistently identified when people are asked to describe what a 'good death' looks like for them.

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While respect for personal autonomy is crucial, we don't exist as individuals in isolation. We exist as part of a society. Our respect for personal autonomy must be balanced by the need to provide strong safeguards and protections for vulnerable people.

That is why we have detailed the 68 safeguards in the legislation.

Specifically, we have heard about concerns regarding those with a mental illness.

The Victorian legislation is clear that a person with mental illness alone would not meet the eligibility criteria for voluntary assisted dying.

However, the Panel decided that a person should not be discriminated against because they had a mental illness but otherwise met all of the eligibility criteria.

The issue is, if there is mental illness, whether it impairs decision-making capacity in relation to voluntary assisted dying.

We need to be careful about distinguishing clinical depression that does interfere with decision-making capacity and depression as a colloquial expression of sadness where decision making capacity is intact.

Patients who are suspected of impaired decision-making capacity must be referred for assessment by an appropriate specialist. In the case of mental illness this is a psychiatrist.

Those judged not to have decision making capacity for the decisions related to voluntary assisted dying will not be eligible.

Some disability advocates have also been vocal in their opposition. I can understand their concern, but we have also heard from others disability advocates who strongly support the legislation.

The legislation has been strengthened by the inclusion of Tricia Malowney OAM as a member of the Panel. Her insights, as a career-long campaigner for disability rights, have been invaluable in guiding us as this legislation was framed.

It is important to remember that the eligibility criteria are based on the diagnosis, not on a disability. The legislation also emphasizes this by stating that, 'having a disability alone does not meet the eligibility criteria.'

However, if someone with a disability, meets the eligibility criteria because for instance of a cancer, they would not be denied access to voluntary assisted dying so long as they satisfy all of the eligibility criteria on the basis of their cancer.

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This brings us back again to the question of why should Australia have Voluntary Assisted Dying.

Opponents of voluntary assisted dying make many claims but the most common one is that palliative care is all we need and that with improved palliative care, everything would be fine.

I am a passionate supporter of palliative care. I have seen the comfort it brings my patients and the care and compassion of those who work in palliative care.

However, I will say again what so many experts from around the world and, indeed, in Australia have said – palliative care alone is not enough to ease suffering in all cases.

The need for this legislation is plainly evident. Many of those most determined to see this law pass have personal anecdotes of loved ones whose death has been terrible.

Not only was the person's suffering prolonged and unbearable but it left deep lingering wounds in the hearts of their family and friends. The impact and depth of those wounds should never be discounted.

People in such examples often died of cancer related illnesses. They experienced excruciating bone pain or neuropathic pain resistant to medication.

Other conditions include chronic organ failure such as end stage respiratory failure or heart failure. Some of the people experience a death akin to slow suffocation or drowning.

We know about devastating neurological conditions such as motor neurone disease or multiple sclerosis that rob a person of almost every personal human dignity and physical ability such that they are no longer able to swallow or breath for themselves.

These people receive specialist palliative care directly or end of life care supported by palliative care consultation and advice.

Palliative care in Victoria, and in Australia, is first class. In Victoria 17000 people each year are supported through community palliative care.

Palliative care is the main game when it comes to what most people want and need at the end of life.

The Panel fully support more resourcing for palliative care. But palliative care is not the answer for everyone.

Palliative Care Victoria and Palliative Care Australia both agree that in about 5% of cases palliative care cannot relieve a person's suffering. This is acknowledged within the palliative care community.

It is for these people this legislation provides a choice.

Voluntary assisted dying and palliative care are not either/or options. Palliative care should be provided based on the needs of the person – not on the end of life choices they may make.

As is the case in other jurisdictions, if a person choses voluntary assisted dying, they continue to be supported by palliative care and their other doctors too. Palliative care can continue right up until the point that the person exercises their choice to self-administer the medication.

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The Parliamentary Committee also heard moving testimony from the Coroner, who described cases of people with terminal illnesses, who were suffering, or fearful of further suffering, who were taking their own lives often in a violent traumatic manner.

Just one example was a 76-year-old man with a diagnosis of cancer who shot himself in the chest with shot gun at home. There were many others.

There are many examples of people illegally importing Nembutal or hoarding other medications to take their own life. Many of these have a terminal illness.

It is not a satisfactory situation where the law is ignored or not enforced, albeit compassionately, with these medications completely unregulated and practices of providing advice and assisting patients to die being carried out in the shadows.

Leaving patients to commit suicide on their own is not an acceptable status quo. It is without oversight or safeguards. It does not protect the vulnerable. It is not compassionate.

Lawrie Daniel is an example of just such a tragic situation. He died last year in aged 51 of multiple sclerosis. He was well connected with the best medical services including palliative care but he suffered tremendously not only with the loss of function but with pain - severe unrelenting nerve pain and muscle spasms. He hoarded medicine.

To protect his family from being complicit, he sent them away for the weekend for a short break. He took his life, alone. Away from his loving wife and children. A sad, lonely death.

It is wrong to say that the status quo is ok. Everything is not ok as it is. Harm is happening now and we have an opportunity to stop it.

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The community overwhelmingly support access to voluntary assisted dying. Every poll over the last decade shows support to be at least 74% and in many cases higher. The recent polling in Victoria, in relation to this Bill, is higher than this.

This is despite a vocal opposition. The arguments are not new. They have been run for a long time and the voices are almost always the same.

At the core, of the majority of the opposition, stated or unstated, is a strong moral objection based on religion.

We have seen a number of religious leaders calling for MPs to not support the legislation even though the majority of those identifying themselves as religious support voluntary assisted dying.

A personal religious opposition is to be respected. But respect for that view is not enough for opponents who want to deny others access to voluntary assisted dying, even though they do not share their religious faith or views,

For some with religious beliefs there is salvific value in suffering. But suffering is a very personal experience.

The question in my mind is why should we impose one view of suffering upon those people who can make an informed and voluntary decision to not experience suffering that is intolerable to them?

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The arguments against are broad ranging but I have been disappointed by their quality and in some cases by their honesty.

A favourite is the “slippery slope”. It is claimed that voluntary assisted dying legislation always results in the law being changed over time to allow more people and more conditions to access voluntary assisted dying.

These are the facts. The numbers of patients in each jurisdiction has increased over time – this is to be expected given aging populations, disease profiles and community acceptance.

In Oregon, which has been in operation for 20 years, the numbers have increased until last year when they went down slightly. The actual numbers themselves remain small with last year only 204 prescriptions being written and 133 deaths with a population of about 4 million people.

In Belgium and the Netherlands there has been an increase in the number of people with mental illness and dementia who have accessed euthanasia laws. As a percentage of the total who access the legislation in those countries, these cases remain a tiny minority.

However, the most important fact here, one often overlooked, is that all of those cases occur within the scope of the existing legislation in those countries.

The legislation in those two countries has always been based on unbearable suffering, not whether a person has a terminal illness. That is why the eligibility criteria in the Victorian legislation are so important.

The legislation in Oregon has been in operation for 20 years and has never been changed. It has formed the basis for other legislation in California, Vermont, Colorado, Washington and Washington DC.

The legislation in Belgium and the Netherlands has been in place since 2002. There has only ever been one change to the legislation.

It is not that people don't campaign for or talk about changes, they do and will always do it as part of a democratic society, but the notion that once a law for voluntary assisted dying is passed, it will invariably change is simply not supported by the evidence from overseas jurisdictions.

The Victorian legislation does not provide access for patients with dementia. It does not allow access through advance care directives. It does not allow access on the basis of a disability or mental illness.

The law with its safeguards, including oversight, would be the most conservative legislation in the world.

On the basis of the Oregon experience, once fully established, the Panel has estimated that after some years, the number of people whose death would be as a result of this legislation would be approximately 150 – 200 per year.

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Vulnerability, particularly of older people, to coercion or a form of elder abuse, is often raised by opponents.

From studies looking at coercion from jurisdictions where voluntary assisted dying has operated for many years the concerns about vulnerable groups have not been fulfilled.

Occasionally, a case study will be thrown up where there is some contortion of the facts that raises concern. In each of those cases, the picture rendered by the opponents is quite different to that of the truth.

Despite this, the Panel have ensured that the Victorian legislation has multiple safeguards to detect and protect people from coercion, even subtle coercion.

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So what about doctors? I am the immediate the past President of the AMA. I am a practicing neurosurgeon and I will talk about this issue from that perspective but I acknowledge that other health professions have their own important perspectives – especially our colleagues in nursing.

As AMA President, I faithfully represented the policy of the AMA on physician-assisted dying which included an acknowledgement was that there was a divergence of views amongst the membership.

In 2016 the Federal AMA surveyed its membership. What doctors acknowledged was that there was pain and suffering could not be relieved in all patients. In fact, almost 70% of members held this view.

When asked if they agreed with the AMA's position that doctors should not be involved in interventions that have as their primary intention the ending of a person's life, 50% agreed. However, 38% of member's surveyed did support it.

When asked whether doctors should not provide euthanasia under any circumstances only 40% agreed and 50% disagreed. That is interesting.

That is what makes this issue such a difficult one for the AMA. In representing the views of some members it risks disenfranchising a significant number of other members.

After my term as AMA President had ended the AMA amended their policy to state that ultimately, this issue is not for the AMA to campaign for or against but rather that it is a matter for society and for government.

When I reflect on the discussions I have witnessed in my various roles, including discussions at the Council of the World Medical Association, two facts strike me.

First was that the mention of vulnerable people and the notion that they might be at risk through such legislation, always resulted in a reaction against voluntary assisted dying.

That innate conservatism of the medical profession has served the public well and is a reflection of the profession's sense of responsibility for their patients.

The flaw in the argument was not to consider the facts, including the details of how legislation could and has been constructed to provide those protections.

The second observation was that the focus was on the morals or views of the doctor rather than the needs of the patient.

The moral views of the doctor and other health professionals must not be ignored. They must be respected, and hence the need in any legislation, to provide the ability of health practitioners to conscientiously object to participating in any aspect of voluntary assisted dying, as is detailed in the Victorian Bill.

Likewise, no health service is obligated to provide voluntary assisted dying as a service. It is up to the health service to decide whether they provide a particular service.

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I have spent my professional life, saving lives of all ages; pushing the boundaries of medicine and of science in help people live. That's what my patients wanted me to do.

In some cases, it's despite knowing that death is inevitable or that a major intervention might only have a small chance of success. But I do it, my colleagues all around the country do it, because we want to help our patients live.

As doctors we walk with our patients. We talk, we hold their hand when it needs holding and we guide them. We support their families. We celebrate the wins but we also grieve with them.

To me, and to many of my colleagues, being a doctor is much more than the practice of medicine. I think most doctors would agree that it is about supporting your patient and it is, about the relieving their suffering.

The Declaration of Geneva, the modern day Hippocratic Oath, states: 'I will maintain the utmost respect for human life.'

Life is not defined by a heart-beat. Life is more. It is the experience of this world, of those around us, it's the love and comfort of our families.

Some might say that suffering is part of life, and I agree it is. But respecting life does not mean that suffering is something that must be endured by an individual, particularly against their wishes.

Respecting life, means also respecting the morals, the wishes and the considered decisions of a person who is dying.

The practice of voluntary assisted dying, which is also primarily about the relief of suffering, when practiced within an established legal framework, is wholly consistent with good medical practice and upholds the fundamental objectives of being a doctor.

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In closing, I want to speak directly to Victorian politicians. I want to thank all of you for the courage you have shown to allow this conversation to happen in Victoria.

Whether you support or oppose voluntary assisted dying, you have provided without question the best, most considered process for this critical issue.

I know that all of you went into Parliament to make a difference. As a doctor I understand this desire. It's what motivates doctors as well.

For some of you, this may be one of the hardest decisions you make in your political career.

But to be able to make a decision, the result of which is to ease the suffering of a person who is dying, and those who love that person, to provide them with the comfort of a choice, not just for one day but for days into the future, that is a unique opportunity for our parliamentarians to exercise.

This is an opportunity not to be wasted.

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I have heard all of the arguments against. The arguments that, in my opinion, do carry weight are those who state their own moral objection. That is fair enough.

But this is voluntary. This is a choice.

Surely there can be no greater injustice than to force a person, who is dying, who makes that voluntary and informed request for assistance, to subjugate their own beliefs to someone else's moral judgement, so as force that person to endure pain, to suffer, until they are dead.

When all of the arguments have been put, I bring us back to the reason that we are here. It is because people are suffering and real harm is happening now.

Australia is a nation of fairness and of compassion.

It is time respect people and their decisions. It is time to allow people to take control of their own death. The legislation is safe. It is compassionate. It is time.

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